

United States Senate Special Committee on Aging
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Chairman Craig, Senator Breaux, and distinguished Members of the Senate Special Committee on Aging, it is a pleasure and an honor to be able to bring you some information about the oral health of seniors and people with disabilities in our country.

I am here as President of Special Care Dentistry. Special Care Dentistry is the only National membership organization devoted to promoting oral health and well being for people with special needs.

Special Care Dentistry has three components: the American Association of Hospital Dentists; the Academy of Dentistry for Persons with Disabilities; and the American Society for Geriatric Dentistry. The reason these three, formerly separate, organizations came together to form Special Care Dentistry is because their members recognize how similar the oral health problems are for the people they serve. This is true whether a Special Care Dentist is someone providing oral health care in a hospital, or someone serving people with disabilities or frail elderly individuals in community setting or nursing home. The financial, physical, medical, or behavior challenges that these individuals may have, has resulted in a nationwide crisis with little or no access to preventive and treatment oral health services.

I want to briefly bring you one story that illustrates what can happen when oral health is neglected. Sarah and her mother could not be here today so I am bringing this story to you electronically. The attached transcript is of a five minute video tape called "Sarah's Story."

Sarah's story illustrates some of the financial and emotional consequences of poor oral health. There is also increasing evidence of the correlation between oral health and systemic disease. Poor oral health is correlated with: coronary artery disease (some studies show four times the risk of death for people with severe periodontal disease); Diabetes; premature delivery and low birth weight; failure to thrive; ischemic stroke; brain abscess; bacterial endocarditis; and respiratory diseases.

So, given the terrible consequences that result from not having dental treatment, why don't people who are disabled and elderly receive the services they need? One factor is the trends in the dental health workforce. Many dentists are busy treating people who don't have financial, physical, medical, or behavior challenges, who they feel better trained to treat, and who they feel more comfortable with.

We know that the dentists retiring today graduated at a time when there were 6000 graduates from dental school each year. They are being replaced with today's 4000 graduates. In spite of these numbers, and in the face of an increasing population, it is still controversial as to whether we are facing a severe dentist shortage or not. I want to point out, as this committee and others analyze this situation, that all the estimates about the dental workforce we have and we need are based on the assumption that those members of our society who are not currently receiving dental services will continue not to receive dental services.

We also need to realize that the availability of dentists trained and willing and able to treat people with special needs is only a part of the problem. There is a general lack of awareness of the importance of dental health and the consequences of dental disease among general health and social service professionals and among caregivers and people with special needs themselves.

There are many innovative systems that have been developed to address these problems. I had the privilege of presenting one of eight "models that work", and the only one addressing oral health issues, at the Surgeon General's Conference on Health Disparities and Mental Retardation two years ago. This "Community-based System" model uses a "Dental Coordinator" to help

develop treatment resources and get people who need those resources into care. You saw the importance of this model in Sarah's Story. It has been very successful in improving oral health in the communities where it is being employed, but it depends on a base of funding through California's adult dental Medicaid system. This system has been threatened recently and does not exist in many states.

So the answer to promoting oral health and well being for people who are disabled and elderly lies in several areas:

- We need to build awareness of the importance of oral health and the consequence of dental disease for people with special needs.
- Awareness must be build through education. We need education for dental health, general health, and social service professionals, and caregivers and the general public. Special Care Dentistry is dedicated to building this awareness through education, but we need help.
- We must provide support to professionals and others who are trying to do the right thing. Many dentists who want to help people with disabilities and frail elderly individuals feel that they are met with nothing but barriers and they give up. The same is true for caregivers and general health and social service professionals.
- Finally we can only be successful in providing awareness, education, and support if there is a base of stable funding for "aged, blind, and disabled" people under our state's Medicaid systems.

I urge this committee and others to support inclusion of adult dental benefits in all of our state's Medicaid systems for people who are "aged, blind, and disabled", our most vulnerable citizens.

Thank you for your time.

Sarah's Story

A videotape produced by:

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Special thanks to Karen Toto, Project Manager

Title:

Sarah's Story

Narrator: Dr. Paul Glassman

“This is Sarah's Story. Fortunately it's a story with a happy ending, but it could have turned out differently. It's a story that illustrates how critical it is for adults who are “aged, blind and disabled” to have basic oral health care coverage under their state's Medicaid system.

Sarah was living in a community residential care facility when this story began. She began to lash out at the other residents of her home. Her caregivers realized that they could no longer guarantee her safety and the safety of other residents of her home. At that point Sarah was admitted to a locked psychiatric facility where the cost runs over \$150,000 a year to the State of California.”

Nadine Hernandez, Sarah's Mother

“My daughter's disability is she was born with Pierre-Robin syndrome and she has autistic tendencies. Sarah communicates in non-verbal way. She has a small grasp of sign language and she uses hand gestures and moanings and groanings to let you know what her needs are. Last year Sarah had a crisis where she was admitted to a psychiatric facility. She's non-verbal so we did not know and she had no way to let us know that she was having dental health problems and she had an infection in her tooth at the time and so it led to her acting out and her behavior became unmanageable. And because of that she was sent to an emergency room and from there a resources center to the psychiatric facility and that's how she ended up there and had that crisis.

This behavior for Sarah was unusual. She had been in a home facility for a while where the women there knew pretty well her behavior and when she was acting out she knew what it was and how to deal with Sarah and how to get information from Sarah and what might have been bothering her. But this was so painful for Sarah that the behavior

became ultra large and where none of us, even I, could figure out what was causing Sarah's behavior too become so bizarre. She was throwing herself into walls, she was physically hurting herself. She was just screaming constantly in pain."

Narrator: Dr. Paul Glassman

"Fortunately for Sarah she lives in a state where there is Medicaid coverage that includes adult dental benefits. In addition, the Regional Center in her area uses the services of a "Dental Coordinator" a specially trained dental hygienist who helps people with disabilities get access to dental services and maintain oral health. Christina Macasiet, The Regional Center's dental coordinator was able to identify that Sarah did have dental problems and find a dentist who was able to treat Sarah."

Nadine Hernandez, Sarah's Mother

"They came in, they did the dental work on her, and within 24 hours she was behaving normally or what we would consider normal for her type of disability whereas prior to that she was physically hurting herself, causing harm to others and throwing herself into walls. If she had not intervened and had not found the resources for Sarah's dental health that today Sarah would be a tragedy. Whereas this story ends up being a story of survival because Sarah did survive, because the resources were there were Sarah. That if she had stayed there in that psychiatric facility I'm not sure where Sarah would be today. I know pretty much where I would be.

My experience with the dental coordinator with the Regional Center was exemplary. As a parent I can only say that if those resources are not set in place for children and adults that need these services, then we are at a loss. As a parent, as a guardian of children with disabilities and adults with disabilities, love can only go so far. At that point we need help. We need outside services. We need outside resources and I have to say how grateful I am that Sarah was able to get those resources."

Cristina Macasaet, Dental Coordinator

"For people with disabilities there is an ongoing struggle nationwide with untreated dental disease due to their inability to communicate, perform daily oral care, and the limited access to dental treatment and services. These individuals are more likely to develop severe dental decay and gum disease. They often times have complex medical and psychosocial conditions that may affect dental treatment and care. These individuals are aging and elderly, are babies born and/or diagnosed with some developmental disabilities. Without adult dental services there will be an increase in emergency room visits and hospitalizations. There will be an extreme financial cost to families and ultimately the public health system.

If Sarah did not have any dental benefits she would still be in that locked facility in La Centinas hospital. She would still be suffering from unnecessary dental pain and undiagnosed dental pain. She would still be taking needless medications to control the

aggressive and severe behavior. If she did not have dental benefits she would not be able to be treated for her dental pain and she would not be in a community care home where she is right now.”

Narrator: Dr. Paul Glassman

“So, Sarah’s story has a happy ending. She is living back in the community Christina is working with her and her caregivers to be sure that she maintains her new dental health.

However, her story illustrates how complicated life can become for someone with a disability who has untreated dental problems and how undiagnosed and untreated dental problems can result in terrible costs to society in dollars and human suffering. We must create funding under Medicaid for all indigent adults who are “aged, blind, and disabled” and support innovative programs to maintain oral health for our most vulnerable citizens.”

Credits:

Thank you to Sarah and her family for allowing us to tell her story. We hope it will help others realize the importance of preventive and ongoing oral health care for people with special needs.

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